



SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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In Memory of a Leader

Former ASCC Commission Chair, Harold O. Thomas of West Memphis died on August 11, 2006, at age 72. Harold was a 30-year-old father of two when he dove into a lake on July 4, 1964. He lived the next 42 years with C5 quadriplegia.

By chance, Harold worked for the St. Francis County Levee District, whose chairman was Maurice Smith. Mr. Smith and his wife, Jane, assisted Harold in getting to NYU Rehabilitation Center, as there was no acute rehab program in Arkansas. As the story has it, Mrs. Smith got then-Governor

Faubus to send Harold in a state National Guard plane to New York.

Harold went on serve as the “silent partner” in the establishment of the Arkansas Spinal Cord Commission (ASCC). He testified in front of the Joint Budget Committee about the need for the Commission in 1974. When the Arkansas Spinal Cord Disability Registry was established in 1977, he was one of the first people listed. Harold served on the Commission from 1975 to 1988, serving as Chair for most of those years. His quiet demeanor

Continued on page 7 - see “Harold Thomas”



Mr. Harold Thomas of West Memphis served on the Commission from 1975 to 1988.

In this issue...

Spina Bifida News	Page 3
Spina Bifida Camp 2006 Was Fun!	Page 3
Congratulations Ethan Cossey!	Page 3
Recent Research in Spinal Cord Injury: The Use of Olfactory Ensheathing Cells	Page 4
Volunteers Needed for Stranded Wheelchair Drivers	Page 5
Do-it-yourself Floor Cleaning . . . from a Wheelchair	Page 5
Up Close and Personal: Leetha Wren	Page 6
Check Out the GameCycle at ICAN	Page 7

New Spina Bifida Research Has Arkansas Connection

A recently published article based on Arkansas mothers, their families and their child with spina bifida provides new insights into the nature of spina bifida. The article titled, *A Reproductive History of Mothers with Spina Bifida Offspring—A New Look at Old Issues*, appears in the journal, *Cerebrospinal Fluid Research*, and was written by ASCC Research and Statistics Manager Tom Farley.

The article studied the reproductive history of 271 mothers residing in Arkansas in 1996 who had a child with spina bifida. The purpose of the study was to present a more complete reproductive history of the mothers and to investigate the nature of spina bifida. The study

found that 24.4% of the mothers had a history of miscarriage; a level three times greater than the general Arkansas population. A miscarriage preceded a female child with spina bifida more often than a male child as compared to live births. Males with spina bifida and a thoracic level lesion conceived by white mothers were at greater risk to be miscarried.

Overall, the mothers gave birth to more affected and non-affected females than males. The article concludes that the cause of spina bifida includes unknown genetic factors, hormonal and/or immune system factors. Go online to <http://www.cerebrospinalfluidresearch.com/> to read additional findings.

SPINAL COURIER

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With Thanks

Donations this quarter from:

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*In Memory of Harold O. Thomas
Annette and Bob Stacy*

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207-5233**

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

From the Director

I'm not big on beauty pageants. As a child of the 60's and 70's, I remember bra burnings, women's liberation and feminism. Those issues put the emphasis on a woman's inner beauty, not outer. I didn't expect Ms. Wheelchair America to be much different from other pageants. But about two years ago I had an experience that changed the way I saw Ms. Wheelchair.

Mare Simonar Dykes of Beebe was Ms. Wheelchair Arkansas. I knew that Mare had grown up with a spinal cord disability and asked her to come speak to our first Spina Bifida Family Fest. She gave a great talk and stayed to visit with everyone. Then, I noticed it—many of the young girls wanted their picture with her, they wanted her autograph, they just wanted to be with her.

Was it the crown? Of course not—it was her inner beauty. A wife and mother of two small boys, accomplished horsewoman and community volunteer, she had engaged these girls—she was a role model. Not many young girls who live with spinal cord disabilities have a lot of role models for life.

So, when Ida Esh't asked me to help bring the 2007 Ms. Wheelchair America (MWA) pageant to Arkansas in 2006, I agreed. Working beside Ida and Mare (and Mare's wonderful husband, Darin, and a lot of other volunteers), we were awarded the 2007 event.

Twenty-seven women from all over the country arrived the first week of August. These were amazing women—college professors, teachers, business owners and rehabilitation counselors—with many accomplishments. Each woman had a 'platform,' a topic she wanted to promote as Ms. Wheelchair America. Those were awesome too: self-esteem, literacy, employment, volunteerism and accessibility.

Over the course of the week, we all had our favorites. You learn a lot about people before they've had their coffee in the morning!

Suffice it to say, these were exceptional women and I learned a lot over the week. But all good things come to an end and at Saturday's Gala, Ms. Massachusetts Autumn Grant was crowned Ms. Wheelchair America 2007.

It was a GREAT EVENT (we're told we 'set a new bar for future pageants'), which brought about 200 people to Arkansas and received a lot of very positive media coverage. I'm glad I was part of it. Sometimes you have to set your bias aside and be open to new ideas.

Cheryl L. Vines

Be sure to vote on Election Day, November 7, 2006!

Spina Bifida News

October is Spina Bifida Awareness month!

- Mark your calendars for the Spina Bifida Association of Arkansas (SBAAR) third annual Fall Family Fest on **October 21st** at Camp Aldersgate. The day's events will include educational sessions, Halloween crafts for kids, lots of educational resources, a great cook out, scavenger hunt and tour of the camp.

- Then on **December 5th**, return to Camp Aldersgate for the annual SBAAR Christmas party. There will be music and singing of carols, gifts for kids and lots of good food. A flyer will be coming out soon.

- SBAAR will team with SBA of Texas and several other regional chapters to conduct the first SBAA Regional Conference in Plano, TX **February 18-19, 2007**. We plan to do some carpooling to get as many folks as possible there! Plan to join us.

- SBAAR awarded five college scholarships this fall. These went to Justin Bickell, Charity Chambers, Aaron Combs, Tyler Garner and Laura Landers.

- A new support group for parents of kids with spina bifida is forming in Springdale, AR coordinated by ASCC Case Manager Maryanne Caldwell. The first meeting was on October 2nd. At present, the group plans to meet the **first Monday of each month** at the Jones Center. For additional information, contact Maryanne at **479-521-1463**.

- Melissa Redman is the new SBAAR web master. Check out the web site at **<http://sbaar.tyepad.com>**

- For more information about the above activities, contact Vicki Rucker at **501-978-SBAA (501-978-7222)**.

Spina Bifida Camp 2006 Was Fun!

This summer, we had 44 campers attend Spina Bifida Camp June 25 to June 30. Campers were divided into two tribes—the Caddo and Quapaw. All week long these two teams enthusiastically competed to earn points in various fun activities.

CenterPoint Energy of Arkansas sponsored the fishing tournament. Everyone who participated was presented with a trophy. The winners of the two main categories were:

Most Fish Caught

First Day

1st place Chelsea Fowler (9 fish)
2nd place Matthew Sherman (5 fish)

Second Day

1st place Layton LaFevers (13 fish)
2nd place Allie Witcher (9 fish)

Biggest Fish Caught

1st place Matthew Sherman (3 lbs 6 oz)
2nd place Layton LaFevers (3 lbs) (tie) JoAnna Moyers (3 lbs)
3rd place Kayla Like (2 lbs 4 oz)

The fun peaked on Friday morning when campers, family members,



Camper Zoe Foy is assisted by Counselor Phil Laney and Volunteer Kelly Allison.

friends and staff filled the Commons Building for the awards ceremony. Each camper received an award. This year's winner of the Joe Morgan Super Camper award was Morgan Love of Little Rock. At last, the winning tribe was announced, and this year's winner was the Quapaw tribe.

Spina Bifida Camp is a collaborative program supported by the Arkansas Spinal Cord Commission, Camp Aldersgate and MedCamps of Arkansas.

If you missed Camp this year, and want to participate next year, be sure to look for details in our January 2007 newsletter, talk with your Case Manager, or contact Mary Jo Stanton by e-mail at mjstanton@arspinalcord.org or call 501-296-1788 or 1-800-459-1517.

Congratulations Ethan Cossey!

Three-year-old Ethan Cossey of Cabot, AR might not have actually played for the Travelers on August 17th, but he sure scored a home run in everybody's heart! Ethan's biggest wish is to go to Disney World and see Mickey Mouse. While at the game at Ray Winder Field he and his family were presented with a check for \$5,000 from the Make-A-Wish Foundation to visit Disney World.

Ethan could not have been more excited. He did get to meet Mickey and Minnie Mouse (*see right*) at the ball field. The family just received news of the Make-A-Wish gift during Ethan's latest hospital

stay. It has been a roller coaster ride dealing with the complications of spina bifida, but now Ethan, his parents and four brothers are ready for all the fun roller coasters at Disney World!



Recent Research in Spinal Cord Injury: The Use of Olfactory Ensheathing Cells

By Tom Kiser, M.D., ASCC Medical Director

One promising research model for repair of the injured spinal cord is the use of olfactory ensheathing cells. These cells can be harvested from the nose of the injured subject and placed in the area of damage in the spinal cord. The olfactory mucosa is readily accessible with minimally invasive techniques, is capable of stem cell like activity, and can aid in neural regeneration.

A case series study of seven patients in Portugal has just been reported in the medical literature.¹ Two of the seven patients, both with tetraplegia, improved from a complete ASIA A to an incomplete ASIA C diagnosis, and one of the subjects regained bowel and bladder function (but was only six months out from the SCI). At six months after transplantation, MRI showed a complete or almost complete filling of the lesion site in all but one subject, and there was no MRI evidence of neoplastic overgrowth in any of the patients.

The olfactory mucosa graft was obtained by an ENT with an endoscope, and the complications were minimal—smell was abnormal, but returned to normal by three months in all the subjects. All but one of the patients had a small improvement in motor return in their legs, but there were minimal functional or independence gains.

In a critique of this study, Dr. Steven C. Kirshblum applauded the researchers for their groundbreaking work, but also pointed out some problems:

1. This human study was undertaken without reported animal model findings to define the functional or neurological benefits of the intervention.

2. Two of the subjects were operated on six months after their injury. This is a time frame when further neurological recovery can be expected, so some of the gains, especially bowel and bladder, could have been due to the natural recovery process.
3. The neurologic improvement reported was in an unusual pattern, and an effort to standardize the neurologic exam between multiple examiners was not discussed.
4. Urodynamic testing preoperatively and postoperatively was not done to document bladder recovery.
5. Greater detail was needed on the surgical procedure to help

We are in an exciting time with several small human studies underway and many anticipated trials in the near future.

researchers better understand the surgical process.

6. None of the researchers or subjects in this study was blinded to the intervention, making objective analysis of the data difficult.

We are in an exciting time with several small human studies underway and many anticipated trials in the near future. Continued progress in spinal cord research is anticipated, and a randomized, blinded, multi-center study will eventually be conducted in the United States.

At each clinic visit, patients and I discuss the latest in research, and the two questions I am frequently asked are: “What is taking so



ASCC Medical Director Tom Kiser, M.D.

long?” and “Should I go overseas to get involved in an implant study?” My answer to date has been to have patience. It is hard to live with a spinal cord injury, and the pull to do something as soon as possible is strong.

But the truth of the matter is that we do not really know what works and what does not work in spinal cord repair. There are a lot of interesting and promising treatment options being tested, and which one or combination of treatments will repair the injured spinal cord needs to be determined before you waste your time and risk your health pursuing every new treatment option.

The other important point to consider is that once you have had surgery with a spinal cord transplant you may not qualify for another treatment protocol if the cure is found. It is important to weigh the risks and benefits of volunteering for a research program. Right now, to travel halfway around the world at this stage of research appears to be too costly in terms of time, money and health risk with only a slight chance of benefit.

Reference:

1. Lima, C., Pratas-Vital, J., Escada, P., Hasse-Ferreira, A., Capucho, C., & Peduzzi, J. D. (2006). Olfactory mucosa autografts in human spinal cord injury: A pilot clinical study. *Journal of Spinal Cord Medicine*, 29 (3), 191-203.

It's that time again. Be sure to protect yourself with a flu shot!

Volunteers Needed for Stranded Wheelchair Drivers

Do you use a wheelchair or other mobility device? Have you been in a situation where your vehicle broke down while traveling and you were left stranded on the roadside because you were unable to get into another vehicle? Did your vehicle have to be towed and you were not allowed to go with it? (Most service trucks will not allow a person to stay in the vehicle while it is towed).

If any of the above has happened to you or you have thought about what you would do in this type of situation, you may be interested in the following.

Several people who have wheelchair-equipped vehicles have

already agreed to participate in an effort to help wheelchair drivers if their vehicle breaks down. Volunteers need to have a van with a lift or some other vehicle that can carry a motorized wheelchair and be willing to help. This is strictly on a volunteer basis.

Your name and contact information will be forwarded to the Arkansas Criminal Information Center. A list of volunteers will be compiled and made available to all 911 and law enforcement agencies.

If a wheelchair driver's vehicle breaks down while traveling within the state, they can sim-

ply call 911 and advise them of their situation. The operator will access the list of participants and contact a volunteer in their area. The volunteer will come to their location with a wheelchair accessible vehicle and transport the driver where they can obtain further assistance.

If you would like to volunteer to provide this service, contact Doug Knight, 871 N. Slemmons, Monticello, AR 71657, e-mail doug_knight@sbcglobal.net or call 1-870-367-2000.

Editor's Note: The stranded wheelchair drivers service is not an ASCC program.

Do-it-yourself Floor Cleaning . . . from a Wheelchair

By Don Bragdon of London, Arkansas

I'm paralyzed with a T12 injury. I live alone in a 2,100 square foot house that has all vinyl floors except for a small, carpeted area. I do most of the housework myself with the exception of tasks that require reaching high places.

After years of cleaning the vinyl floors with Mop & Glow®, a waxy buildup was getting to be a problem. The floors looked darker, dirty and had no shine.

I decided that I was going to accept the challenge of cleaning the floors myself. Now, as anyone in a wheelchair knows, this wasn't going to be easy.

I decided to purchase a Hoover® FloorMate™ SpinScrub™ after seeing a TV advertisement for one. The ad showed how the unit would first vacuum the floor, scrub it with a cleaning solution and then suck up the dirty solution. The unit does this by using

two containers. Water or dirt is vacuumed into the lower unit while the upper unit applies cleanser, wax or just plain water.

The price was a little high (about \$170) but there wasn't another comparable vacuum on the market at the time.

Once I had the FloorMate, I started out by purchasing a gallon of Johnson Floor Stripper. I diluted the stripper per instructions with water and applied it evenly to the floor with a sponge mop. I let it soak for five to seven minutes and then used the FloorMate to suck up all the grime into its lower container. I then sprayed clear water from the upper container and the unit sucked up that water, leaving a very clean floor.

With the entire floor clean, I applied a mixture of Murphy® Oil Soap and water. My routine was to scrub with soap and water while

pushing the unit forward and then to suck up the dirty wastewater on the way back. When finished the floor dried to a nice shine.

I did adapt the FloorMate to make it easier for a person in a wheelchair to use. The unit has a pedal on the base that has to be pushed by foot to lower the handle. Of course, being in a chair, I had to bend way down to release the pedal with my hand. So, I made a lever in my shop and installed it on the side on the unit. Now all I do is push down on the lever to lower the handle.

The floors now shine like new. When people come over to visit and ask if I had a new floor installed, I just grin and say, "No, I cleaned them myself!"



Photo courtesy of <http://www.hoovercompany.com>

Up Close and Personal: Leetha Wren

This is the twelfth in a series of articles profiling the ASCC Case Managers.



Leetha Wren began her Case Management duties in the ASCC Batesville office in November 2004. She currently provides services to individuals in a ten county area in North Central Arkansas. "As I visit the individuals in my area," Leetha stated, "I am often reminded of what my grandmother once told me. 'It is a privilege to be invited into someone's home and you should always honor that.' Treating individuals with respect goes a long way in establishing good working relationships and we as Case Managers should always remember that."

Leetha has been a dedicated state employee for almost 24 years. Previous to her employment with ASCC, Leetha worked for Services for the Blind, Children's Medical Services and the Employment Security Division. She holds a Masters degree in Social Work from UALR Graduate School of Social Work.

After spending two years providing case management services to individuals with spinal cord disabilities her advice to any new Case Manager is that they should always remember, "You can never catch up, as there is always something that needs to be done." Client Services Administrator Patti Rogers commented, "Leetha provides excellent support to the persons on her caseload. She has a positive outlook and a great sense of humor, which helps smooth the way in difficult times. We are very fortunate to have found Leetha."

PROFILE:

Date And Place Of Birth: April 28, 1958, in Batesville, AR

Family Members: My parents and their five cats: Pinky, Silky, Molly, Clifford James Oreo (Jimmy Reo) and Rehab

If I Did Not Live In Batesville, I Would Want To Be: Traveling the world

I Absolutely Will Not Eat: Liver

One Thing People Would Find Surprising About Me Is: I'm a big fan of the PBR (Professional Bull Riders, Inc. — "the toughest sport on dirt")

My Favorite Movie Is: Any classic comedy, such as *Arsenic and Old Lace*

My Favorite Song Is: *Over the Rainbow*

I Am Most Comfortable With People Who: Are easygoing and have a good sense of humor

My Favorite Pastimes Are: Reading, television and movies, shopping (garage sales, estate sales, etc.)

The Best Advice I Ever Received Was: "Do unto others as you would have them do unto you"

My Favorite Saying Is: "Make it work for you"

I Knew I Was Grown Up When: I don't recall a defining moment, so maybe it hasn't happened yet!

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Work at Disney World

One Word To Sum Me Up: Appreciative

Harold Thomas

Continued from page 1

and friendly smile won over many legislators. Harold was the leader in an effort by the Commission to establish the Arkansas Spinal Cord Injury System and an SCI Rehabilitation Center.

"If Jane Smith was the godmother, Harold Thomas was the 'godfather' of our Commission," said ASCC Executive Director Cheryl Vines. "He served our Commission in so many ways over the years, we may not have existed, except for Harold's cool head and business acumen."

West Memphis Case Manager Sharon McCoy relates her first day on the job at ASCC, "I was at the office on my first day and I got a call, 'Sharon, I know you are busy on your first day, but could you come over to the Levee District office—RIGHT NOW?' I was scared to death! It was only a few miles away and I raced over, only to be met by a very distinguished gentleman who just wanted to meet me and to let me know he was there to help." Over the years he proved to be a great help.

Harold served many other Arkansas institutions, as Chairman of the Boards of Directors of Crittenden Memorial Hospital, Arkansas State University and on the Board of East Arkansas Enterprises. After his injury, Harold returned to his job at the St. Francis Levee District and worked until his retirement last year.

Harold is survived by his wife, DeFaye, his son, Harold, Jr., daughter, Cary, and his grandchildren, who were the lights of his life.

The members and staff of the Arkansas Spinal Cord Commission honor Harold and extend our sincere sympathy to his family.

Check Out the GameCycle at ICAN

Want to change your exercise routine from boring to fun? How about burn fat and build muscle while playing video games? Sound too good to be true? It's possible with the GameCycle®, a new addition to the Increasing Capabilities Access Network (ICAN) Clearinghouse of Technology.

The GameCycle is a hand-cranked stationary cycle that powers a Nintendo® GameCube. It was designed to help persons with paraplegia build their upper-body strength, aerobic capacity and motor and cognitive skills.

Users crank and steer the GameCycle like a hand-cycle, and those motions control Nintendo GameCube racing-style video games. The faster a user cranks the GameCycle, the faster the car in the video game goes. Users control the car's turns, not with a joystick but by twisting and tilting the GameCycle's handgrips (which come in varying types for different hand functions). The GameCycle's resistance can be adjusted to make it easier for beginners or harder for advanced users. The GameCycle is compatible with a wide variety of racing-style Nin-

tendo games that can be purchased at any store that carries computer games. Compatible games include *Need for Speed Underground*, *Racing Evolution*, *Monster 4X4 Masters of Metal*, *Mario Kart Double Dash*, *Kirby's Air Ride* and *Crash Nitro Kart*.



Barry Vuletich, ICAN Program Director, tries his skills exercising to the *Need for Speed Underground* game on the GameCycle.

The GameCycle can also be hooked up to another unit so users can compete against their nondisabled friends. For a demonstration of the GameCycle or to schedule a "workout" call ICAN at **501-666-8868** or **1-800-828-2799**. ICAN is a program of Arkansas Rehabilitation Services located at 26 Corporate Hill, Little Rock, AR 72205.

Skip Green

Continued from page 7

environment so the combination with vitamin C makes it more effective. It is less effective against bacteria that are urea-splitting and that increase the pH (e.g., Proteus and some Psuedomanas species). Side effects can be nausea, gastric distress, rash and dysuria.

*Use is **contraindicated** in dehydrated patients, and those with severe renal disease or hepatic insuf-*

*ficency. Crystals can develop in the urine if urine output is decreased. **Avoid use in gout** because it can cause urate crystals to precipitate in the urine. **Do not use with sulfa medications** because the sulfonamides may form insoluble sediment in the bladder. If you are using Acetazolamide, the Methenamine is ineffective since it causes the urine to be alkaline.*

*This may be a good medication for someone with recurrent bladder infections, but **you need to be aware of the above limitations.**"*



The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you “should have done but didn’t.”

Skip Green of Fayetteville, AR tells us how he keeps his urinary tract infections (UTI’s) under control.

I’ve had my fair share of UTI’s over the years—bad ones with the dreaded shakes and high fevers. I’m sure some of you can relate. Seventeen years ago an Urologist started me on an antibacterial drug named Methenam (*Methenamine Mandalate*). It’s taken with vitamin C and plenty of fluids to create acidity in the bladder that wards off bacteria leading to infections.

The Urologist told me that it was once a very popular drug for nurs-

ing home residents many years ago in combating UTI’s, but fell to the wayside mainly because the people taking it were not getting the proper amount of vitamin C and fluids.

He started me taking 3 Methenam tablets a day with vitamin C and fluids. Over the past 15 years I’ve weaned myself to taking 1 tablet with a 500 mg vitamin C tablet first thing in the morning, followed by a couple cups of coffee. Friends, I’ve

had 3—count’em, three—UTI’s in the past 17 years. Knock on wood! If you’re plagued with UTI’s ask your urologist/physician about Methenam. It could work for you too! A special thanks to that Urologist.

Editor’s Note: I checked with Tom Kiser, M.D., ASCC Medical Director, who said, “Methenamine or Mandelamine is bactericidal and hydrolyzes to formaldehyde in the urine. It is active only in an acid

Continued on page 7 - see “Skip Green”

We invite you to send in your helpful hint—your bit of “grease.” Contact your ASCC Case Manager, write us at *Spinal Courier*, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at courier@arspinalcord.org

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